

## Special Thoughts

*By Gay Robin Labrum*

I am a special parent. This is because I have a child with special needs. His name is Joshua and he was born on September 10, 1993. He has curly red hair and brown eyes. He has a passion for music, loves to hear me sing, adores his father, James, and his best friend is Eeyore (character from Winnie the Pooh). He has epilepsy, cerebral palsy, a severe hearing loss, and a clubfoot (corrected with surgery). He also has a gastrostomy tube for feeding, and a tracheotomy. Joshua's brain injury is due to a knot in his umbilical cord resulting in a lack of oxygen at birth. He does not walk or talk, but he still has the best smile and laugh in the world.

Caring for him sounds like a lot of work, and it is. Some days during his first year-and-a-half seemed overwhelming, but Joshua is good-natured, and that makes a difference. I have always looked for words of wisdom to inspire me and keep me strong in times of adversity, and my experiences with Joshua have taught me a lot. I have some wise words that I would like to share with other parents of special children. I hope they help.

- **Take it one day at a time.** We can only live one day at a time.
- **Keep the faith.** Pray a lot.
- **Cry when you need, as often as you need.** Release your feelings. Talk to someone; friends, family, support groups, and psychologists all help. Talking to a family counselor has opened the communication channels between my husband and me, and we talk much more freely these days.
- **Don't be discouraged! Doctors don't know everything.** Wonderful things still happen. Put these words up in a place where you can read them often.
- **Make sure you get enough sleep.** Nap during the day or get someone to watch your child so you can get some sound sleep. It is essential to your emotional harmony.
- **Pamper yourself.** Treat yourself like someone special. People have said to me, "Take care of that baby!" and I ask them, "What about me?" Take care of yourself. Do not get so caught up in caring for your child that you neglect your inner self. You are important to your child, your family AND yourself, so remember to do things

for yourself. Go for a walk. Take a bubble bath; start reading your favorite books; start a craft; play the guitar; dance; whatever. Enjoy all the things that make you a special person.

- **Forget the housework.** Care for and enjoy your child NOW. The housework will still be there.
- **Remember the present is precious.** Deal with problems as they arise and don't worry about any possible future problems. Don't get caught up in "what ifs". We can only live with today. Love your child today.
- **Follow your intuition.** Most of the time, parents DO know best, even better than the best doctor. After all, you know your child better than anyone else. Listen to your inner voice.
- **Keep your sense of humor and your perspective.** James and I say that it's not always easy having a special child, but we love that handicapped parking spot!
- **Take time to be alone with your spouse.** At least once a week, for several hours, be with each other. Keep your marriage alive and strong and you can triumph over anything.
- **Keep up-to-date medical records!** This included evaluations, medication lists, and telephone numbers of key medical and support personnel. ALWAYS take this information with you when your child goes into the hospital. It is invaluable to the doctors and nurses.
- **Ask everyone lots of questions.** Do not be intimidated. This is YOUR child and you have a right to ask and to know what's going on.
- **Do not compare your child with other children.** This is a hard one, but it is necessary. Every child is special. If your child progresses at a different rate, so what? Everything your child accomplishes is wonderful and special, because it takes more effort than that of a "normal" child. Be proud of your child and his accomplishments.
- **Do not feel guilty or ashamed.** Tell people that you have a child with special needs. Be tolerant and open to questions. Help people to understand disabilities.
- **Get to know your child.** Learn to see past the disabilities. James was a little scared to get close to Joshua when he was born, but this past summer, when I was very ill, James had to take

care of Joshua and he got to know him as a person. They bonded, and now they are best buddies.

- **Give yourself credit.** Give yourself a pat on the back twice a day.
- **Always hope for the best.** Look for the positive.
- **Never give up.** Your child will progress to his highest skills as long as you are there to stimulate, give encouragement and love.
- **Don't be intimidated by therapists.** They are there to give you suggestions, so talk with them. Tell them how YOU are feeling what your strengths and limitations are. Do what you can during the day and be glad for what you accomplished. Don't feel guilty for what you didn't do. You can only do so much therapy. You must be a loving parent first. Perform bits and pieces of therapy throughout the day and have fun with your child.
- **Some days, just do the minimum.** You may be exhausted and stressed and all you can do is the minimum. So, DO the minimum-and nothing else. When I have been up several times the previous night I get very tired and usually spend the next trying to get extra sleep in between caring for Joshua. When I am emotionally drained, it's all I can do to take care of Joshua and nothing else. I've learned that it's okay. You do not have to be "super parent." You are human.
- **Gain strength from you child's inner strength.** A mother once told me, "If my daughter can go to therapy and not cry, so can I." My son Joshua is a fighter. He wouldn't have survived this long if he wasn't. He is a strong child, and we aren't giving up.
- **Treat your child the way you would want to be treated yourself.** Then you will know you have done your best.
- **Be glad you have a child.** There are some couples who don't have any children and might be jealous. Remember the adage, "The grass is always greener on the other side of the fence." Be glad for what you have.
- **Don't neglect your pets.** Give them attention, and help them to know your child, too. After all, they are a part of your family and they can help stimulate the child. Joshua has two older "brothers," the cat and the dog.

- **Savor the special moments.** The first time Joshua cuddled in my arms, I felt his contentment and I felt such love for him it was just wonderful. A bond is created that cannot be broken and will only grow stronger with time.
- **Be patient and gentle with your child.** Your child did not ask to have a disability. Don't take your frustrations out on your child.
- **Notice the beauty in the world.** Don't get so caught up in caring for your child that you forget everything else. Be aware of the peace that can be found in seeing a glorious sunset, smelling a beautiful flower, the coolness of a rain shower, and even the smile of a stranger. Share the world's beauty with your child.
- **Be happy.** Accept that your life will be different, but no less wonderful than anyone else's life. Life is a journey and an adventure, not a destination. It is what YOU make it. Learn to view your child's problems as obstacles to be overcome. James and I say that Joshua's life is an obstacle course, and we will help him run it.
- **Make note of your own insights.** As you grow with your child, you will find your own personal bits of wisdom. Write them down so you can read them often. They will keep you strong.

These are some of the thoughts that have helped me through the day more than once. We have a lifetime of Joshua ahead of us, and we will collect more wise words of courage and fortitude. Joshua is a very happy boy and making progress every day. Life will not always be easy, but it will never be dull or boring. We are on an adventure through life with him, and that is a pretty good place to be. I am content. I am happy. I am a special parent.